

Dehydration and provision of fluids in palliative care

What is the evidence?

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OBJECTIVE To provide a clinical review of issues surrounding reduced fluid intake in palliative care patients and a practical approach to care for these patients.

DATA SOURCES MEDLINE was searched from 1980 to 1995 for articles concerning dehydration in dying patients. In addition, the law databases QUICKLAW, WESTLAW, and MEDMAL were searched.

STUDY SELECTION Key papers were included for discussion in relation to the clinical evidence to treat or withhold treatment and to a representative sample of the social, ethical, and legal issues.

SYNTHESIS There is little clinical evidence to guide patients, families, or clinicians in treating with reduced fluid intake during the terminal phase of life. Assisting patients to take fluids as a social or symbolic act is recognized, as is the ethical and legal stance that assisting fluid intake should be thought of as a medical therapy.

CONCLUSION Without sound evidence upon which to base clinical decisions, patients, families, and clinicians are left to balance potential benefits and burdens against the goals of care.

OBJECTIF Procéder à une revue clinique des aspects entourant l'administration de liquides en petites quantités aux patients recevant des soins palliatifs et offrir une approche pratique aux soins de ces patients.

SOURCE DES DONNÉES Recension sur MEDLINE d'articles publiés entre 1980 et 1995 sur la déshydratation des patients mourants. Recherche également dans les bases de données QUICKLAW, WESTLAW et MEDMAL.

SÉLECTION DES ÉTUDES Les principaux articles retenus ont servi à alimenter la discussion et à rechercher des preuves cliniques à l'appui ou contre cette forme de traitement à la lumière d'un échantillon représentatif d'arguments sociaux, éthiques et juridiques.

SYNTHÈSE Il existe peu de preuves cliniques pour guider les patients, les familles ou les cliniciens dans leur décision d'administrer ou non des liquides en petites quantités pendant la phase terminale. On reconnaît que le fait d'aider les patients à boire est un geste social ou symbolique, tout comme le sont d'ailleurs les prises de position éthique et juridique voulant que l'aide à l'ingestion de liquide soit considérée comme un traitement médical.

CONCLUSION En l'absence de preuves convaincantes sur lesquelles on pourrait fonder les décisions cliniques, il appartient aux patients, aux familles et aux cliniciens de décider en fonction des avantages et désavantages potentiels dans un contexte d'objectifs de soins.

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FOANNE LYNN, PHYSICIAN AND ETHICIST, refers in her book, *By No Extraordinary Means*,¹ to the thousands of ethical decisions we make daily as patients, families, and clinicians. These decisions, although just as painstakingly difficult as decisions like unplugging ventilators or assisting suicides, never make the headlines or spotlight. One of these is the decision to provide supplementary fluids to dying patients.

When is it clearly appropriate to take such action? When is it not? How should decisions be made in the large gray area in between? This article outlines the problem, discusses the factors that bear on the decision making, and proposes a strategy for clinicians facing such situations with patients.

Until we began to hospitalize all dying patients, the idea of artificially providing fluids was not an issue. Those with advanced disease died in their homes among their families with as much comfort as was possible with the knowledge available. As hospitalization occurred more frequently, techniques were developed to provide fluids in a variety of ways: intravenous tubes, nasogastric tubes, gastrostomy tubes, and hypodermoclysis.

The more our culture denies death, the more we seem to intervene at the end of life. Rarely is there systematic inquiry about the efficacy of such techniques, or examination of the desired outcomes: prolongation of life or the enhancement of quality of life through relief of symptoms. Indeed, of those dying in hospital of cancer in one study, 70% had an IV line running at the time of death.² Not many therapies continue to be used so broadly today without evidence of efficacy.

In the late 1970s and early 1980s, palliative care in Canada and hospice care in the United Kingdom and United States began modern development. Most programs provided no assisted fluids, yet patients did not appear to suffer from dehydration. How can the two realities, hospice approach to dying and hospital approach, be reconciled? Each reality brings strengths to the care of the dying that are important to family physicians trying to help patients and families make informed decisions.

Data sources

MEDLINE was searched from 1980 to 1995 using the terms "dehydration," "palliative treatment," "hospice care," and "parenteral therapy" (all MeSH headings). The Canadian law database QUICKLAW and the American databases WESTLAW and MEDMAL were searched using the terms "withdrawal of food," "feeding," "hydration," "nutrition," and "cancer." Unlike MEDLINE, these databases have no thesaurus, and cases are searched for the existence of the terms. The references of each article retrieved were also reviewed.

Study selection

Articles were considered if they critically assessed patients' experiences of symptoms (eg, case reports, case series, or more sophisticated research designs) or if they exemplified the range of opinions held about social, ethical, or legal issues. Far more opinion papers and ethical or legal analyses exist in the literature than were included for review.

Synthesis

Clinical evidence. Thirst, dry mouth, nausea, vomiting, and fatigue are the symptoms clinicians and patients consider most likely to be associated with inadequate fluid intake at the end of life.³ In a cross-sectional study of two palliative care units, these symptoms were explored quantitatively.⁴ Fatigue was the most severe symptom experienced. Thirst and dry mouth were rated moderately severe, and nausea and vomiting were reported to be fairly minimal.

In this same study, researchers attempted to explore the association between the volume of fluid intake and the severity of the so-called dehydration symptoms. No association could be found. In other words, fluid intake did not predict the severity of symptoms. The study had limitations of borderline sample size and the inability to include most of the terminally ill patients because of competence or cognition problems.

McCann and colleagues⁵ recorded the symptom experience of 32 patients dying of cancer or stroke for 75% of their terminal period. Sixty-two

percent of these patients experienced either no thirst or thirst only initially on admission that was easily relieved with oral fluids or ice chips. They also reported that 97% of patients said they had either no hunger or hunger only initially.

Ellershaw and colleagues⁶ present results of what appears to be another cross-sectional study examining symptoms of 82 patients, most of whom were taking inadequate oral fluids and who died, on average, 2 days later. The researchers could not demonstrate an association between clinical dehydration and symptoms of dry mouth, thirst, or respiratory secretions. Again, this study had the problem of small numbers, which could mean a significant association was missed.

In a case series by Musgrave and associates,⁷ 30 patients were initially entered into a pilot study to examine thirst among hospice patients dying with IV fluids. Only 19 subjects were able to rate the symptom in the last 24 hours of life. No statistical testing was conducted on this small sample, but the authors report no trends appearing in the symptom experience and the amount of fluids provided. The design of this pilot study was very weak, lacking any significant variability in IV fluid intake.

The other symptom receiving recent attention that could be linked to fluid intake is cognitive impairment.⁸ That the elderly who become dehydrated also become confused is not news to most family physicians. A small but elegant study by Phillips et al⁹ demonstrated that even the healthy elderly, when dehydrated, have much less perception of thirst and dry mouth than younger control subjects. One could interpret this to mean not only that dehydration might be a cause of cognitive impairment but that the elderly, when dehydrated, do not suffer the way clinicians might think. Because most palliative care patients are elderly, this becomes a possible protective mechanism in terminal dehydration. As Yan and Bruera⁸ reveal in case reports, however, perhaps we should routinely think of dehydration as a cause of cognitive impairment among dying patients.

In their 1995 historical case series, Bruera and colleagues¹⁰ reviewed the extent of impaired mental status of inpatients before and after implementing opioid rotation and much broader use of rehydration. Their observations drew more attention to this potential association. More rigorous methods must be employed to obtain results that will allow more confidence in this association.

At the descriptive level (not based in research), clinical benefits and burdens of artificial hydration are reported. Potential benefits are reduced thirst, dry mouth, and nausea; reduced cognitive impairment; and prolonged survival,⁸ although no evidence substantiates these claims. Potential burdens are repeated needle punctures, increased respiratory secretions, congestive heart failure, edema, raised intracranial pressure, tumour swelling, nausea and vomiting (in gastrointestinal obstruction), and increased ascites (if it already exists).³ Again, no evidence, other than anecdotal, supports these claims.

Evidence that symptoms are not severe and are not associated with the amount of fluid or food intake is scant but is growing. Studies such as these are difficult to design with such very sick people. If we are to make informed, evidence-based decisions, however, research in this area must continue.

Sociocultural issues and symbolism.

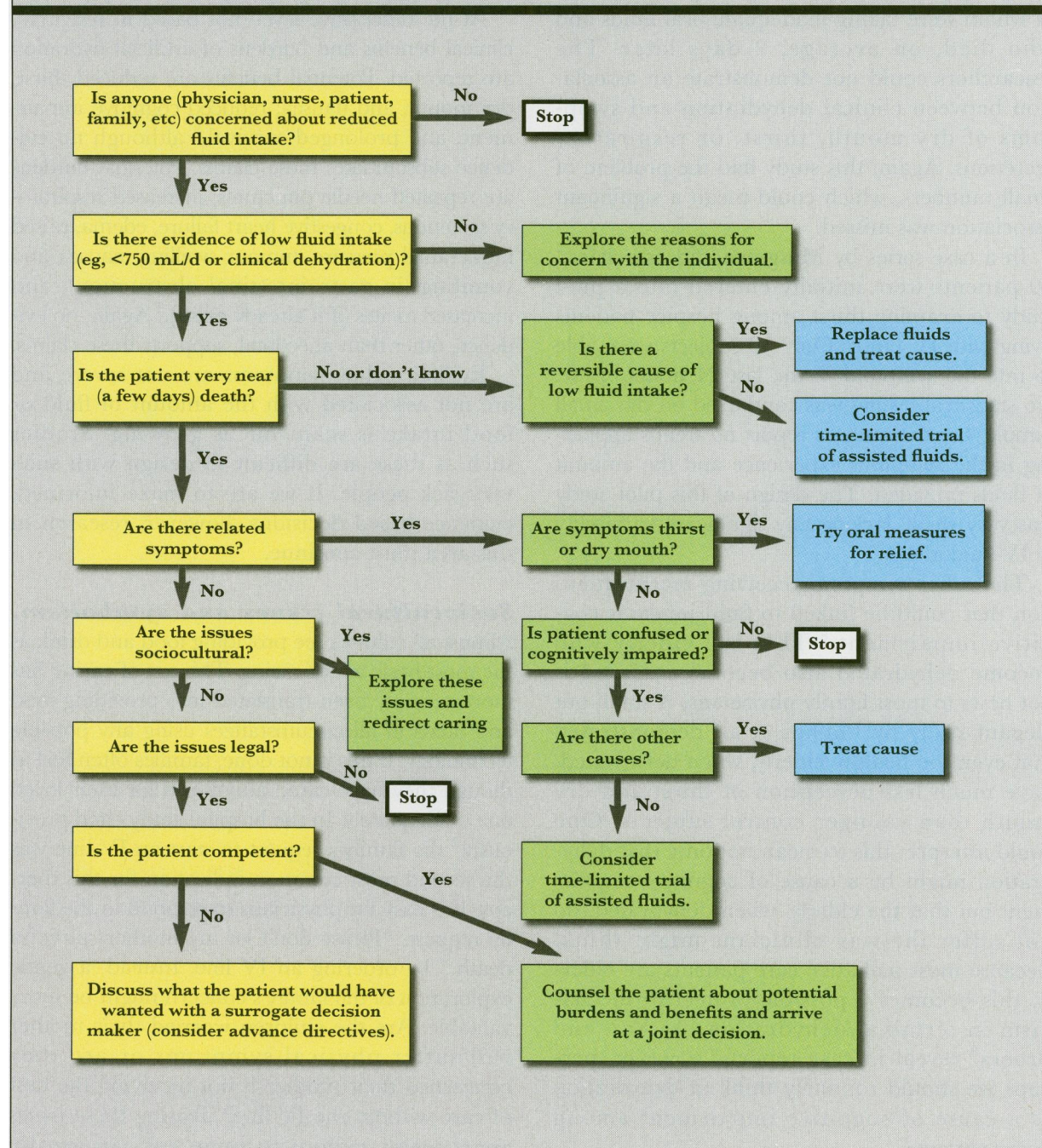
Almost all cultures see providing food and drink as the most basic act of caring. This act of caring has more recently been translated into providing food and fluids in all circumstances using any possible technology. If this is not done, families often feel as though they have cared about and for their loved one inadequately. In the hospital study cited previously,² the family's request to start an IV line was the second most common indication for this therapy. It is easy for physicians to respond to the family request, "Please don't let my mother starve to death," by ordering an IV line. Instead, a gentle exploration of the family's concern might be more valuable. Are the children worried their mother will suffer physical symptoms or are they concerned their mother is not receiving the best of care without the IV line? Teasing these issues apart seems tedious to some but can greatly

facilitate the physical care required at home or in hospital.

Wilson,¹¹ in her detailed qualitative exploration of why one daughter chose a feeding tube for her mother, found four issues swayed the daughter's choice. They were an urgency to make

a decision, ignorance of the mother's preferences about tube feeding, ignorance of the technique, and the belief that the tube feeding would not prolong her mother's life or suffering. Although there are no such studies in relation to IV fluids, I believe the issues are fundamentally similar.

Figure 1. Assisted hydration in dying patients



Exploring the goals of care at a given point could facilitate decision making. If a patient is still early in the terminal care period and recovery from low fluid intake can be anticipated with treatment of a concurrent condition, then the goal becomes restoration of function, and fluid replacement is clearly indicated. For someone within 24 to 48 hours of death, comfort is likely the appropriate goal, and fluid replacement less likely to be indicated. Patients, families, and physicians who explore goals of care together as the disease progresses will more easily make appropriate decisions.

Ethical issues. Is it morally acceptable to deny fluids to dying patients? This issue has been debated most openly in the context of patients who are severely cognitively impaired.⁸ The arguments are, however, similar and, I believe, somewhat easier when one is faced with certain impending death. The chance for recovery or even the hope of maintaining current quality of life is virtually non-existent for most patients with advanced cancer. If patients are competent and have been informed of the role of assisted fluids and the goals of care, clearly they have the right to deny such treatment if offered.

For the same patients who demand fluids, the situation seems more difficult. If there were clear scientific evidence that assisted fluids did no good or even potential harm, clinicians would have support for denying such futile treatment. This would be comparable to not offering any other futile treatment. The evidence that fluids relieve symptoms or that dehydration causes suffering is weak. Competent patients and clinicians must then make a decision in the face of such weak evidence. This is the gray area. A time-limited, goal-centred therapeutic trial of assisted fluids is then an option.

When patients are incompetent, the decision is really not much different, or should not be much different. Families or surrogate decision makers may decline offered treatment, including assisted fluids, if they know the patient would have wanted to decline. Potential problems occur when families wish to show caring by asking for assisted fluids when their desire goes against previously

stated wishes of the now incompetent patient. Once again, physicians should explore and redirect the desire to care away from technology and toward other activities, which might include skin care, mouth care, talking with the patient, or simply being at the bedside.

When the potential benefit of assisted fluids is unclear, a time-limited, goal-centred trial could also be considered. It is now generally agreed that, if a therapy is judged futile or if providing such therapy causes more burden than benefit, it is ethically acceptable to offer no therapy.¹²

Legal issues. Assisted fluids, as described in the opening of this paper, are viewed in the North American medicolegal climate as therapies.¹³ As such, it seems they are legally required to be offered when appropriate and to be denied if they would cause more harm than good. As with other therapies, they can be refused by competent patients, and they can be withdrawn in likely futile situations (ie, near death). No legal precedent could be found specifically for withholding assisted fluids in terminal care in Canada.

In a thorough review of precedent-setting case law from Canada, the United States, and England, Gilmour¹⁴ describes the three current approaches courts seem to take when considering the withdrawal of "life support" from those no longer able or competent to express their wishes. These approaches are advance directives, substituted judgments, and the best interests test. In advance directives, the wishes of patients are known from a written document. In substituted judgments, people near to the patients describe, from foreknowledge of the patients, what the patients would want in such a situation. In the best interests test, the court must decide, given current societal standards and values, whether sustaining existence is in the best interest of the patients or whether existence, if full of suffering, is worse than death. No Canadian precedent for terminally ill cancer patients could be found.

Physicians' approach. When fluid intake falls below what is expected, when a potentially reversible cause offers a real possibility for

restoring quality and quantity of life, and when the patient and family agree, fluids should be provided until the patient is once again self-sustaining. If the potentially reversible cause does not resolve, the issue should be reviewed. Potentially reversible conditions leading to temporary low fluid intake include gastrointestinal obstruction (first event primarily), hypercalcemia, oral disease, infection, and excess or adverse effects of some medications.

If the cause is not reversible and the patient is very near death, one must consider the potential burdens and benefits. In all likelihood, the former outweigh the latter in such situations, and assisted fluids should not be provided. The one difficult situation is cognitive impairment in patients likely near death. Assisted fluids may or may not reduce this impairment, but the remaining quality of life must also be considered.

When the death is not imminent, the cause of low fluid intake is not readily reversible, and there are distressing symptoms, a time-limited, goal-centred trial of assisted fluids should be considered. The rate and amount of fluid delivered should be decided upon jointly by clinicians and patients with their families. The goals of care (eg, reduced thirst, less confusion) should also be decided upon. Finally, the time to see results should be confirmed. If there is no progress toward those goals after that time, the therapy should be stopped (*Figure 1*).

Conclusion

Those who state with conviction that either providing or withholding assisted fluids for dying patients is correct have little evidence upon which to base a claim. Without such evidence to guide clinical practice, decisions must be made integrating the best evidence available; the clinical situation; the wishes of the patient and family; and society's ethical, legal, and social consensus.

Rarely is the answer to whether to hydrate patients artificially a definitive yes or a no but rather a judgment as to what end and at what cost. An open mind and open communication are the keys to the best decisions. ■

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